

CHAPTER 11

NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

11-1 LEGAL AUTHORITY

In accordance with Title III, Part E of the Older Americans Act (OAA), as amended in 2006, the Assistant Secretary shall carry out a program for making grants to States with State Plans approved under section 307, to pay for the Federal share of the cost of carrying out state programs to enable area agencies on aging, or their providers to provide multifaceted systems of support services --

1. for family caregivers; and
2. for grandparents or other older individuals who are relative caregivers.

The National Family Caregiver Support Program (NFCSP) shall be accessible and provided throughout each of the planning and service areas in Tennessee. The NFCSP in Tennessee shall be provided in accordance with the Older Americans Act Amendments of 2006 and policies in this manual.

11-2 CLIENT POPULATION DEFINITIONS

The person receiving services in the NFCSP is the caregiver. The NFCSP provides an opportunity to develop a service delivery system to respond to the needs of our caregivers. The following are the client population definitions:

(1) Family Caregivers

Family caregiver means an adult family member, or another individual, who is an informal provider of in-home and community care to an older individual or to an individual with Alzheimer's disease or a related disorder with neurological and organic brain dysfunction.

(2) Grandparents and Relative Caregivers

Grandparent or older individual who is a relative caregiver means a grandparent or step-grandparent of a child, or a relative of a child by blood, marriage, or adoption, who is 55 years of age or older and –

- (a) lives with the child;
- (b) is the primary caregiver of the child because the biological or adoptive parents are unable or unwilling to serve as the primary caregiver of the child; and
- (c) has a legal relationship to the child, such as legal custody or guardianship, or is raising the child informally.

11-3 OTHER DEFINITIONS

- (1) Child means an individual who is not more than 18 years of age or who is an individual with a disability (this covers children 19 – 59 years of age with disability).
- (2) Disability refers to conditions attributable to mental or physical impairment, or to a combination of mental and physical impairment which results in substantial functional limitations in one or more of the following areas of major life activity: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, economic self-sufficiency, cognitive functioning, and emotional adjustment [see 42 USC 3002 (8)].
- (3) Greatest Economic Need means the need resulting from an income level at or below the poverty line (100%) as defined by the Office of Management and Budget and adjusted by the Secretary of Health and Human Services.

- (4) Greatest Social Need means the need caused by non-economic factors which include—physical and mental disabilities; language barriers; and cultural, social, or geographic isolation, including that caused by racial or ethnic status, that—restricts an individual’s ability to perform normal daily tasks; or which threatens his or her capacity to live independently.
- (5) Frail means, with respect to an older individual in a State, that the older individual is determined to be functionally impaired because the individual –
- (A) (i) is unable to perform at least two activities of daily living without substantial human assistance, including verbal reminding, physical cueing, or supervision; or
- (ii) at the option of the State, is unable to perform at least three such activities without such assistance; or
- (B) due to cognitive or other mental impairment, requires substantial supervision because the individual behaves in a manner that poses a serious health or safety hazard to the individual or to another individual.
- For the state of Tennessee, we have adopted (A)(i) having a minimum of two (2) ADL limitations or (B) has a cognitive or other mental impairment that requires substantial supervision to prevent harm to self or others.

11-4 SERVICE COMPONENTS OF THE NFCSP

Nationally, the program was created to establish an infrastructure of program resources and assistance to family caregivers. Tennessee, working in partnership with the nine (9) Area Agencies on Aging and Disability (AAAD) and local

community-service providers shall provide five categories of services for family caregivers.

- (1) Information Services (1 activity) – A service for caregivers that provides the public and individuals with information on resources and services available to the individuals within their communities. (Service units for information services are activities directed to large audiences of current or potential caregivers such as disseminating publications, conducting media campaigns and other similar activities);
- (2) Access Assistance
 - (a) Information and Assistance (1 contact) – A service that assists caregivers in obtaining access to the services and resources that are available within their communities. To the maximum extent practicable, it ensures that the individuals receive the services needed by establishing adequate follow-up procedures.
 - (b) Case Management (1 hour) – Assistance either in the form of access or care coordination in circumstances where the care recipient is experiencing diminished functioning capacities, personal conditions or other characteristics which require the provision of services by formal service providers or family caregivers. Activities of case management include such practices as assessing needs, developing care plans, authorizing and coordinating services among providers, and providing follow-up and reassessment, as required.

- (c) Outreach (1 contact) – Intervention with individuals initiated by an agency or organization for the purpose of identifying potential caregivers and encouraging their use of existing services and benefits.
- (3) Individual counseling, organization of support groups, and caregiver training (1 session) – To assist the caregivers in the areas of health, nutrition, and financial literacy, and in making decisions and solving problems relating to their caregiving roles. This includes –
 - (a) Individual Counseling – A person qualified by training or experience and licensure must be designated to supervise the service. The service must be supervised by a counselor licensed by the State of Tennessee. Licensure can be verified at www2.state.tn.us/health/licensure/index.htm. Licensure includes: Licensed Professional Counselor, Licensed Clinical Social Worker, Licensed Clinical Psychologist, or PhD. A person qualified by training or experience can deliver the service. (See Attachment B for Service Description)

Area Agencies must have counselors who they can refer caregivers to if there is a need.
 - (b) Support Groups – Programs that offer sessions in which caregivers discuss their attitudes, feelings, and problems and with input from other members of group, attempt to achieve greater understanding and adjustment and explore solutions to their problems.

- (c) Caregiver Training – Training/education that is designed to assist caregivers with acquiring knowledge and skills that will help them in providing care.
- (4) Respite Care – Services which offer temporary, substitute supports or living arrangements for care recipients in order to provide a brief period of relief or rest for caregivers. Respite care includes in-home respite such as personal care, homemaker; respite in a non-residential program such as adult day care; and institutional respite provided by placing the care recipient in an institutional setting such as a nursing home for short period of time as a respite service to the caregiver; and (for grandparents) summer camps.

Transportation of the care recipient to an adult day care center or similar program would be part of the respite expense.
- (5) Supplemental services – Services provided on a limited basis to complement the care provided by caregivers. Examples include, but are not limited to, home modification, home-delivered meals, medical equipment and supplies, personal emergency response system (PERS), incontinence supplies, and assistive technology. Service definitions and standards are found in the TCAD Guide to Contract Preparation and Reporting.
 - (a) Legal assistance is a supplemental service. Counseling including training sessions on legal issues would be considered legal assistance and should be reported as a supplemental service.

- (b) Transportation to medical appointments would be a supplemental service.

11-5 PRIORITY

In providing services, priority shall be given to:

- (1) Caregivers who are older individuals with greatest social need, and older individuals with greatest economic need (with particular attention to low-income older individuals);
- (2) Older individuals providing care to individuals with severe disabilities, including children with severe disabilities;
- (3) Family caregivers who provide care for older individuals with Alzheimer's disease and related disorders with neurological and organic brain dysfunction; and
- (4) Grandparents or older individuals who are relative caregivers who provide care for children with severe disabilities.

11-6 ELIGIBILITY

Information, Assistance, and Counseling can be provided to any caregiver, but Respite and Supplemental services funded under the NFCSP can be provided only if the older care recipient meets the definition of frail. Respite and Supplemental services that are not supported by Title III-E (and state or local matching funds) are not bound by this eligibility restriction. Any of the five NFCSP service categories may be provided to grandparents, step-grandparents, and other older relative caregivers caring for a child.

Non-citizens are eligible to receive services through the NFCSP. In accordance with AoA guidelines, non-citizens, regardless of their alien status, should not be

banned from services authorized by the OAA and administered by the AoA based solely on their alien status.

11-7 AREA PLAN

Each AAAD must have a multi-faceted program that includes all five services (Information; Access Assistance; Individual Counseling, Organization of Support Groups, and Caregiver Training; Respite; and Supplemental services) for caregivers. AAAD do not necessarily need to use NFCSP funds for all five services if other funding is available to cover a service and it can be documented. The area plan must include detailed information on plans for the agency to provide or make available to caregivers each of the five services.

The decision to provide grandparent or relative caregiver services is up to each AAAD. If an AAAD plans to provide services to this population, those services should be detailed in the area plan.

Approval of the area plan by the Tennessee Commission on Aging and Disability (TCAD) constitutes authorization for the area agency to provide services. If the area agency wishes to initiate new services during the plan period, a plan amendment must be submitted to the Commission on Aging and Disability for approval.

11-8 FUNDING LIMITATIONS

- (1) No area agency may use more than ten percent (10%) of its award to provide Title III-E services to grandparents and older individuals who are relative caregivers of a child who is not more than 18 years of age.

Services provided to grandparents or relative caregivers providing care for adult children with disabilities, who are between 19 and 59 years of age

shall not be counted against the 10% ceiling for grandparents and other caregivers.

- (2) No area agency may use more than twenty percent (20%) of its award to provide supplemental services. Supplemental services are flexible enhancements to caregiver support programs designed for the benefit of caregivers. Each area agency can elect supplemental services based on local needs as long as they are included in the area plan and approved by TCAD.

11-9 MAINTENANCE OF EFFORT

Funds made available under the NFCSP shall supplement, and not supplant, any Federal, State, or local funds expended by a State or unit of general purpose local government (including an AAAD) to provide services described in Title III, Part E, Section 373 of the Older Americans Act.

11-10 ADMINISTRATIVE REQUIREMENTS

- (1) The State Agency shall:
 - (a) Designate a coordinator to implement and oversee program development of the NFCSP statewide.
 - (b) Develop and maintain consistent standards and mechanisms for the NFCSP to be implemented statewide. These standards and mechanisms shall be used to assure the quality of services provided in accordance with the Older Americans Act, Administration on Aging regulations and policies and Tennessee Commission on Aging and Disability policies and rules.

- (c) Adopt standard individual assessment tools to be used by all planning and service areas throughout Tennessee.
 - (d) Collect, maintain, and report information pertaining to the NFCSP to the Assistant Secretary for Aging of Department of Health and Human Services.
 - (e) Provide training at least annually to the family caregiver program staff.
 - (f) Provide technical assistance as needed.
 - (g) Assume quality assurance responsibilities for all caregiver programs to ensure compliance with standards, policies, and procedures of the State Agency and the Older Americans Act.
- (2) At a minimum each Area Agency on Aging and Disability shall:
- (a) Assess the needs of caregivers in the PSA and develop and submit an area plan (or update) reflecting local needs to the Commission outlining the services to be provided at least annually.
 - (b) Publicize NFCSP services to ensure that individuals throughout the area know about the availability of the services.
 - (c) Provide caregiver information and referral, and screen individuals for caregiver support services.
 - (d) Complete an in-home assessment on individuals whose screening indicates need for respite or supplemental services.
 - (e) Arrange for the provision of individually needed family caregiver services directly and/or through local service providers.

- (f) Maintain current database of programs and services, regardless of funding stream, which a person needing caregiver support services might find useful.
 - (g) Organize new and/or coordinate with existing caregiver support groups and caregiver training events.
 - (h) Have counselors who they can refer caregivers to if there is a need for Individual Counseling.
 - (i) Coordinate the NFCSP with other programs and service systems serving persons with disabilities.
 - (j) Make use of trained volunteers to expand the provision of the five service components.
 - (k) Attend training planned or approved by the State Agency.
 - (l) Ensure appropriate program/financial reporting, billing and budget reconciliation.
 - (m) Negotiate contracts and provide quality assurance program implementation.
 - (n) Compile, maintain, and report waiting lists of persons requesting caregiver services for which service is not available.
- (3) Service Providers
- (a) Each provider shall adhere to the Tennessee Commission on Aging and Disability Policies and Procedures for Programs on Aging and shall provide services in accordance with the NFCSP procedures.

- (b) Each provider shall comply with all the provisions of the service descriptions as established by the Commission (See TCAD Guide to Contract Preparation and Reporting).
- (c) Attend training provided by or approved by the State Agency or Area Agencies on Aging and Disability.
- (d) Each provider shall maintain adequate records to evaluate service provision to insure responsible fiscal management.
- (e) Each provider shall maintain and submit program data and statistics as required by the Area Agency.
- (f) Forms utilized by providers shall include all information required by the Area and State agencies.

(4) Consumer's Right to Self-Determination

All individuals have a right to choose how they will live, as well as where they will live, as long as they are competent to make that decision and are able to understand the consequences of their actions. All adult individuals are presumed legally competent unless they have been deemed incompetent by a court. It is essential, however, to guard against allowing a participant to continue to live in an environment or situation that is clearly unsafe. While it is essential to assist people however possible, National Family Caregiver Support Program personnel are not expected to assist a person in continuing to live in a situation that is unsafe or to make plans that are unrealistic and unsafe.

Reports to Adult Protective Services are mandated by state law when "any person" has reasonable cause to suspect abuse, neglect (including self-

neglect) or financial exploitation. This includes neighbors, friends, relatives, doctors, dentists, caregivers, agency personnel, etc. (Adult Protection Act T.C.A 71-6-103(b) (1); [www.state.tn.us/humanserv/adpro.htm].

11-11 REPORTING REQUIREMENTS

TCAD will prepare and submit to the Assistant Secretary reports on data and records related to the program including information on the services funded under the NFCSP, and standards and mechanisms by which the quality of the services are assured. The reports must describe any mechanisms used by TCAD to provide to persons who are family caregivers, or grandparents or older individuals who are relative caregivers, information about and access to various services so that the persons can better carry out their care responsibilities.

The AAAD is required to report both programmatic and fiscal information to the TCAD in a manner specified in writing by the TCAD. The federal fiscal year is October 1 through September 30.

The NFCSP section of the State Reporting Tool (SRT) shall be submitted quarterly by the 20th day of the month following the end of the quarter. When the due date falls on a weekend or holiday, the report will be due on the following business day. Required reports must be submitted to TCAD according to the instructions, schedule and form(s) provided. The year end report should include data for the entire fiscal year.

Each AAAD shall maintain program data and client information as required by the State Agency. For each service that is provided through the NFCSP, including individual counseling, support groups, and caregiver training, the

AAAD must enter demographic data about the caregiver into database in order to count. An aggregate number may not be entered. Demographic data should include the following:

- (a) Name
- (b) Address
- (c) Phone number
- (d) Age
- (e) Gender
- (f) Race/Ethnicity
- (g) Rural status (usually determined by AAAD based on address information)
- (h) Name and relationship to the care recipient.

The only service that is excluded from entering demographic data is Group Information. For this service an aggregate number can be entered.

For Individual Counseling, Support Groups, and Caregiver Training a unit of service is equal to a session. Each caregiver will receive a unit of service for each session they attend.

Information and Assistance to caregivers is an access service that: (A) provides individuals with information on services available within the communities; (B) links individuals to the services and opportunities that are available within the communities; (C) to the maximum extent practicable, establishes adequate follow-up procedures. Internet web site “hits” are to be counted only if information is requested and supplied.

Home-delivered meals served with Title III-E funds may be counted as a Nutrition Services Incentive Program (NSIP) eligible meal “if” the meal:

- (1) Meets the requirements of the OAA (Title III-C),
- (2) Is served by an agency that has a grant or contract with the State Unit on Aging (SUA) or AAAD; and
- (3) Is served to an adult qualified for service under Title III of the OAA:
 - (a) Care recipients, who are age 60 or older;
 - (b) Caregivers, who are age 60 or older; or
 - (c) Caregivers, regardless of age, who are the spouse of a care recipient who is 60 or older.

11-12 LONG DISTANCE CAREGIVERS

There are two types of long distance caregivers:

- (1) The caregiver lives within the State of Tennessee and the care recipient lives in another State.
- (2) The caregiver lives in another State and the care recipient lives within the State of Tennessee.

Caregiver services may be provided to long distance caregivers whose care recipient resides within the State of Tennessee if funds are available. However, the decision to provide Respite and Supplemental services to long distance caregivers will be done on a case-by-case basis and must be pre-approved by Commission staff.

Title III-B or Title III-C in-home services or state funded Home and Community Based Services should be considered first if the care recipient is eligible to receive services under those programs.

If the caregiver resides in Tennessee and the care recipient resides within another state, the area agency should make a referral to the area agency in the State where the care recipient lives.

11-13 VOLUNTEERS

Each AAAD shall make use of trained volunteers to expand the provision of the five service components. AAAD should work in coordination with organizations that have experience in providing training, placement, and stipends for volunteers or participants (such as organizations carrying out Federal service programs administered by the Corporation for National and Community Service), in community service settings. Such programs include Senior Corps and AmeriCorps (VISTA).

11-14 ASSESSMENT AND REASSESSMENT

If a screening indicates a caregiver's need for respite or supplemental services, a Home and Community Based Services (HCBS) assessment shall be completed on the caregiver as well as the care recipient prior to receiving services. There will be two client records created, one for the caregiver and one for the care receiver.

All assessments and reassessments must be conducted in the home. Reassessments should be done every six (6) months or as needed. Follow-up calls should be made quarterly to ensure that the needs of the caregiver are being met.

Respite and Supplemental services provided through Title III-E must comply with policies and procedures of the service being provided. For example, a caregiver and/or care recipient who receives home-delivered meals through the NFCSP must comply with Nutrition guidelines.

SERVICE DESCRIPTION

Service Name: Group Information

Service Category: Information Services

Service Description: A service for caregivers that provides the public and individuals with information on resources and services available to the individuals within their communities. (Service units for information services are activities directed to large audiences of current or potential caregivers such as disseminating publications, conducting media campaigns and other similar activities)

Service Unit: 1 activity (Regardless of the number of people that attend the session, it is still 1 unit of service per activity.)

Service Activities: The purpose of Group Information is to raise public awareness of services available. The goal is to educate caregivers about services and resources that could assist them with care needs. One way to get information out is to collaborate with other organizations that come in contact with caregivers such as churches, community clinics, hospitals and hospice activities in order to tap into the caregiver market.

Minimum Standards:

1. A person qualified by training or experience must be designated to supervise the service.
2. Group information staff must maintain current information on benefits and services available in the community.
3. Adequate records must be maintained to record and evaluate service provision to insure responsible fiscal management and to provide timely and accurate required reports.

SERVICE DESCRIPTION

Service Name: Individual Counseling

Service Category: Individual Counseling, Organization of Support Groups, Caregiver Training

Service Definition: This service is designed to provide counseling, advice, guidance, and support to caregivers. This could include mental health counseling and support to help caregivers cope with the stresses of caregiving.

Service Unit: One session

Service Activities: Individual counseling is designed to assist the caregiver one-on-one with making decisions and solving problems that are related to their caregiving roles.

Minimum Standards:

1. A person qualified by training or experience and licensure must be designated to supervise the service. The service must be supervised by a counselor licensed by the State of Tennessee. Licensure can be verified at www2.state.tn.us/health/licensure/index.htm. Licensure includes: Licensed Professional Counselor, Licensed Clinical Social Worker, Licensed Clinical Psychologist, or PhD.
2. A person qualified by training or experience can deliver the service. The person designated to deliver the service must be supervised by a counselor licensed by the State of Tennessee.
3. There must be an organizational structure with clear lines of supervision, approved position descriptions, established job qualifications and clear assignment of all functional tasks.

4. Satisfactory procedures must be established to recruit, train, schedule and evaluate qualified staff (paid and volunteer).
5. Satisfactory procedures must be established to interact and coordinate services with other agencies or service providers to assure there is no overlapping or duplication of services and that service is delivered economically.
6. Adequate records must be maintained to record and evaluate service provision, to insure responsible fiscal management, and to provide timely and accurate required reports.
7. Satisfactory procedures must be established to protect confidentiality of records which include a person's name and personal information and to obtain and record the individual's informed consent prior to the release of personal information.

SERVICE DESCRIPTION

Service Name: Support Groups

Service Category: Individual Counseling, Organization of Support Groups, Caregiver Training

Service Description: Programs that offer sessions in which caregivers discuss their attitudes, feelings, and problems and with input from other members of group, attempt to achieve greater understanding and adjustment and explore solutions to their problems.

Service Unit: One session

Minimum Standards:

1. A person qualified by training or experience must be designated to facilitate support group meetings.
2. Support groups must be provided in locations and at times that are easily accessible to diverse caregivers.
3. Adequate records must be maintained to record and evaluate service provision, to insure responsible fiscal management, and to provide timely and accurate required reports.
4. Support groups are to be conducted by the service provider staff or by other qualified personnel obtained by the service provider.
5. Satisfactory procedures must be established to ensure that all information is kept confidential within the group.
6. Satisfactory procedures must be established to recruit, train, schedule and evaluate qualified staff (paid and volunteer) to perform the service.

SERVICE DESCRIPTION

Service Name: Caregiver Training/Education

Service Category: Individual Counseling, Organization of Support Groups, Caregiver Training

Service Definition: Training/education that is designed to assist caregivers with acquiring knowledge and skills that will help them in providing care.

Service Unit: One session

Service Activities: Education/training can include activities such as one-on-one or group training to increase personal care skills, community workshops, education forums, lectures, training on long term care planning, and video trainings.

Minimum Standards:

1. Service may only be provided by persons qualified by education and/or experience.
2. Service must be provided in locations and at times that are easily accessible to diverse caregivers.
3. Adequate records must be maintained to record and evaluate service provision, to insure responsible fiscal management, and to provide timely and accurate required reports.
4. Satisfactory procedures must be established to recruit, train, schedule and evaluate qualified staff (paid and volunteer) to perform the service.